

# They Were Still Here: Archives and Online Grief Communities

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Dr. Jennifer Douglas, iSchool@SLAIS, University of British Columbia  
[jen.douglas@ubc.ca](mailto:jen.douglas@ubc.ca) @archivingeye

# Outline

- The community
- The role of recordkeeping
- Affordances of online community
- Issues and responsibilities

This presentation discusses stillbirth and associated trauma.

This presentation is given in memory of my second daughter, Anja.

# The community: Stillbirth and stigma

- Stillbirth: the death of a fetus at 20 weeks gestation or older, in utero or in labour
- Occurs in 7 per 1000 births in Canada (Joseph et al, 2013)
  - SIDS = 1 in 2000 live births
- Loss is minimized and misunderstood (Cacciatore et al, 2008)
- Parents feel isolated and their grief is **disenfranchised** (Lang et al, 2011)
- Characteristics of online grief communities: sense of stigmatization; limited access to other support networks (Swartood et al, 2011)

# The role of recordkeeping: Asserting 'realness'

- “He was a real baby, with real baby things.” (Layne, 2002)
- “For the parents of stillborn babies, *things* perform a critical role. Things function as the tangible, earthly connections these parents have with their babies, a means of creating memories of and social identities for their children since the corporeal child no longer exists and often goes socially unrecognized...The things she touched, that were a part of her, are *sacred*. We hoard them, **treat them with the reverence of archivists.**” (Weaver-Hightower, 2012)

# Online grief communities

- Community websites, often including forums to which parents can contribute (e.g. MISS Foundation – [www.missfoundation.org/support/programs/forums](http://www.missfoundation.org/support/programs/forums))
- Facebook groups and pages
- Linked blogs
- Use of twitter hashtags (e.g. #stillbirth, #babyloss)

# Collective memory, conspiracy, aspiration...

- “There is no collective memory of this life and there will be no narrative of growing up.” (Godel, 2007)
- Blogging as conspiracy: pact between bereaved parents
- Archives “are not only about memory (and the trace or record) but about the work of the imagination.” (Appadurai, 2003)
- As they conspire together, bereaved parents both (1) perpetuate the memory of their babies and (2) create evolving identities for them

Commemoration + aspiration + community = **collective memory**

# An example: the birthday post

- “I would like to celebrate and remember Baby [name ]...He turns a year old today in our hearts. Happy birthday, sweet little [name ]. You’re loved, you’re cherished, and oh, so, so missed.”
- “I will say [his] name and light a candle for him...”
- “I’m sorry [his birthday] isn’t what you had hoped his first birthday would be like...cupcakes and a messy face, or something equally adorable...”
- “[His] name was said beneath a beautiful aspen tree in Colorado...”
- “A very Happy Birthday was said to [ name] in Germany...”
- “Happy birthday baby [name ]...Your name is said out loud and in our hearts here in the UK. You are missed terribly.”

# A continuing social existence

- “[Photographs], artefacts and the narratives associated with them reflect attempts to create memories and bonds...Through these [images and narratives] a biography is created from imagined, or wished-for, rather than lived, experience.” (Godel, 2007)
- “Web 2.0 based technology...is not simply a passive tool for merely depicting the deceased but seems to offer some parents **a means of continuing the social relationship to their child, indeed, in some sense, of maintaining and enlivening that child.**” (Mitchell et al, 2012)



# Issues and responsibilities

- Ethical concerns:
  - The archive as a continuation of its creator's (or subject's) social existence
  - Anonymity and pseudonymity in the community
  - Communities as 'safe spaces'
- Responsibilities:
  - Archives of trauma
  - Archives of feeling (Cvetkovich, 2003)
  - Grief as a universal emotion
    - Countering pathologization
    - Possible contribution of experts on recordkeeping and preservation?

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